

Extension of School Augmentative and Alternative
Communication Services to Home: A National Survey

By
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Abstract

This study examined support parents were given by school personnel after their school-aged child received a speech-generating device (SGD) to communicate. The study investigated whether parents received support and if so, the nature of the support. The study also explored the type of support parents would like to have received. An online survey was created. This survey was distributed through a variety of organizations that focus on supporting families with children with disabilities. A total of 19 parents responded to the survey in its entirety and provided information on support.

A majority of parents were offered support after their child received an SGD. This support most frequently came from a speech-language pathologist who most often had also completed the assessment. Support was most often provided during an in-person meeting, which the parents reported as having worked well. The most common area of support provided was help with navigating the SGD; however, the areas parents desired more information about included customization of the language software, technical support, and support in terms of increasing the child's use of the SGD.

Clinical implications for speech-language pathologists include the importance of seeking information from families about the support they would like in terms of the SGD. This includes providing the support in the mode of the communication that is most beneficial for the family. Each family may have different needs, which should be considered in order for the SGD to successfully transition from school to home.

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Chapter 1

Introduction

The educational setting continues to be a place of change in terms of the type and variety of language and speech therapy services offered and the technology provided to benefit students' communicative needs. However, what has not changed is the necessity for open communication to exist between therapists, educators, and families (McNaughton et al., 2008). This communication allows parents to know how their child is progressing at school and also understand how they can help to support their child in the home environment. Speech-language pathologists do not travel with their student to all of their different settings, so it is vital to have parents find value in and understand the services being provided in order for carryover to occur to other settings. This concept of "carryover" plays a role for speech-language pathologists in terms of language and speech development for their students. Without carryover, the changes that occur in a speech and language therapy setting do not automatically transfer to other settings or provide lasting effects for the students in their long-term communication development (McLay et al., 2015). Carryover is how speech-language pathologists can identify the progress of the students and is necessary in order for significant change to occur. For carryover to occur, the entire team supporting a student must be part of the process and understand the importance of the child's ability to communicate throughout his/her day in various settings. This is especially important for students with complex communication needs who use speech-generating devices (SGD).

The support a student receives outside the therapy setting impacts the student's overall success with using an SGD (Lund & Light, 2006; 2007b). It is important for students with

complex communication needs who use speech-generating devices to use them both at school and at home to communicate (McLay et al., 2015; Sigafoos et al., 2004). Students who use SGDs need to be able to effectively and efficiently communicate in all settings. To this end, parents need to have an understanding of how to support their child's alternative mode of communication (Sigafoos et al., 2001). Thunberg, Ahlsén, and Annika (2011) found positive effects at school when parents were engaged with SGDs at home. It is the role of the speech-language pathologist to facilitate this transition and support parents so that they can be active members of the team. The speech-language pathologist provides support of the SGD at school and then should support the transition to using the device at home through involving the parents. A lack of training about device use by speech- language pathologists is often noted in the literature (Bailey, Parette, Stoner, Angell, & Carroll, 2006; Starble, Hutchins, Favro, Prelock, & Bitner, 2005). Successful transition from school to home depends on the speech-language pathologist, whose knowledge base should include SGDs. Without support, many families are not able to keep up with the new demands of communicating with an AAC device and thus device abandonment occurs (Cockerill et al., 2013).

Speech-Generating Devices (SGDs)

To understand SGDs, it is important to first define them, examine the population who needs them in schools, and then examine how they have changed over time. SGDs fall under the category known as augmentative and alternative communication (AAC). The American Speech-Language-Hearing Association (ASHA) defines AAC on their Practice Portal as follows: "AAC uses a variety of techniques and tools, including picture communication boards, line drawings, speech-generating devices (SGDs), tangible objects, manual signs, gestures, and finger spelling to help the individual express thoughts, wants and needs, feelings, and ideas" (ASHA, n.d.a). One

form of communication is an electronic device that generates speech output, an SGD. In much of the literature reviewed in this study, SGDs were identified with the label of AAC. Therefore, the wording will match the studies and will switch between AAC and SGD.

Students with complex communication needs often use a variety of AAC systems including signs, gestures, photos, and vocalizations to communicate (Beukelman & Mirenda, 2013; Cockerill et al., 2013). To say that a student has complex communication needs means that the student cannot meet his/her daily needs with speech. An SGD can be helpful for those students who lack speech or are limited in speech abilities, whether the loss is temporary or permanent (Sigafoos, Schlosser, & Sutherland, 2013). Students with etiologies that contribute to the need for SGDs to meet daily communication needs can include individuals with Down syndrome, autism, cystic fibrosis, neurofibromatosis, and Angelman syndrome. Without the use of an SGD, students with complex communication needs are often limited in their interaction within their communities. SGDs can help promote participation by increasing communication skills, which increases overall quality of life (Clarke & Wilkinson, 2008; Lund & Light, 2006, 2007). All individuals have the right and need to develop meaningful relationships with those around them (e.g. family members, teachers, and peers) and SGDs contribute to the development of these relationships.

As technology has changed through the years, the complexity of AAC has grown and a wide variety of devices exist. Now tablets, such as iPads, are included as SGDs due to the downloadable communication applications that they can support (Kagohara et al., 2013; Sigafoos, O'Reilly, Lancioni, & Sutherland, 2014). One of the benefits of having a wide variety of SGDs is that the devices can be more easily transportable, which was a need noted by parents (Parette et al, 1996). However, beyond transportation, individuals who use SGDs have highlighted the need

for the devices to be dependable and reliable (Shepherd, Campbell, Rezoni, & Sloan, 2009). The use of tablets is becoming more accepted in the community as technology continues to transform the way we live. A variety of layouts exist for AAC devices and each student's motor abilities and communication skills should be taken into consideration when determining the best device for that student (Gevarter, et al., 2013; Marshall & Goldbart, 2008). Depending on specific needs, students can make selections on the SGD through various modes including making a direct selection, using eye-gaze, or by operating a switch. Regardless of mobility, devices now exist that can support students with complex communicative needs. For students requiring AAC, this leads to SGDs being part of all aspects of their life, including school. School is often the place where an SGD is first used with a student.

SGDs and School

The ASHA 2016 Speech-Language Pathologists Schools Survey (2016) showed that 51.5% of 810 speech-language pathologists in elementary schools and 56.4% of the 198 speech-language pathologists in secondary schools regularly served clients who are nonverbal. The mean number of students served was three for elementary schools and a four for secondary schools. It is becoming more common for speech-language pathologists to be working with students who communicate using AAC, such as an SGD.

An SGD is necessary for many students who have complex communication needs in order for them to be successful in the educational setting. Without an SGD, these students struggle to communicate in an efficient and effective manner, which is needed to meet many of the curriculum standards. This right to communicate in the educational setting is protected through the Individuals with Disabilities Education Act (IDEA) 2004. IDEA recognizes and mandates that assistive technology, such as AAC, be provided to students as needed. IDEA states an assistive

technology service as “any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device” (H.R.135, SEC602[2]). Speech-language pathologists usually provide assistive technology services related to communication.

Part of the process of a student receiving an SGD and support accessing the general education curriculum involves an Individualized Education Plan (IEP) for the student. As mandated by IDEA, parents are considered part of the IEP team and should be present for meetings regarding their child. The Family Empowerment and Disability Council (2012) provides information about what parental involvement means when it states:

Key components of the original law and its reauthorization in 2004 include parents’ rights under due process procedures; parent participation in Individualized Education Program (IEP) planning; home-school collaboration; and decision making opportunities for parents in all aspects of their child’s education, including evaluation, placement, and service implementation (p. 1).

The schools are legally obligated to include parents, which should provide the opportunity for speech-language pathologists and family members to begin collaborating.

All students must be able to access the general education curriculum. For those students who are unable to communicate effectively, the speech-language pathologist can support the student and other school personnel in facilitating the student’s ability to access the curriculum. Parrish and Stodden (2009) studied three students who were provided with choices regarding their educational objectives. The students in the study benefitted from being able to be a part of their own goal setting. The students were engaged and their motivation to work increased as they began to master curriculum standards (Parrish & Stodden, 2009). Robinson and Soto (2013)

encourage speech-language pathologists to consider that study in their intervention when working with students who use AAC systems in accessing the curriculum.

Research has addressed whether the location of support impacts students with disabilities. This would most likely include individuals who use an SGD to communicate. McLeskey and Waldron (2011) evaluated high-quality instruction in both the general education room and the special education classrooms. The authors found that the location of services was less important than the quality of instruction the students were receiving. This is true of the services of speech-language pathologists as well. Their services can occur in a variety of environments as needed by the student.

SGDs and Family

The use of an SGD affects more than just the student with complex communication needs; it also impacts the family. Consequently, families need to be involved in the assessment and intervention process. An overarching theme in the research with families indicates that parents want to be considered in terms of the device chosen for their child (Parette, Brotherson, & Huer, 2000; Cress, 2004). Parette and Brotherson et al. (2000) found that families were concerned that recommendations about AAC use were based on the short-term contact that a speech-language pathologist had with a student, rather than the parent's input that is based on the daily life of the child. A parent's input is needed in order to get a more complete view of the child and the child's strengths (Cress, 2004). In addition, it is important to analyze what factors influence AAC use for a family. These factors include: training on an SGD device, identifying SGD technology barriers, noting support from the community, understanding the impact of an SGD on a family, and determining a link between the child's abilities and the SGD to best meet his/her needs (Marshall & Goldbart, 2008; McNaughton et al, 2008; Shepherd et al., 2009; Clarke et al., 2011).

Hidecker (2010) examined AAC use at home for 55 children ranging from 15 to 75 months. About half of the systems the children used included voice output. Hidecker (2010) found that only 4% used direct select on complex SGDs either “often” or “always” to communicate. When considering the 19 children who used SGDs in the study done by Hidecker (2010), 42% of the children always used their SGDs at home while 11% of the children did not use their SGDs at home. The study did not investigate whether supports made a difference in home use; however, this study did indicate that device use at home is not consistent and not always seen as important.

Family-centered intervention places a focus on understanding each family and determining what supports would be most beneficial. This form of intervention often helps to guide assessment and intervention for children with SGDs (Cress, 2004). Cress (2004) describes family-centered services as “viewing the family as the unit of service delivery, recognizing child and family strengths, responding to family-identified priorities, individualizing service delivery, responding to the changing priorities of families, and supporting family values and lifestyle” (p. 53). Cress (2004) acknowledged that even when family-centered intervention is the goal, disagreements may arise between the family and the speech-language pathologist in terms of what is best for the child. Families want their input, perceptions, and knowledge about their child to be taken into consideration during the assessment and intervention involving SGDs.

Mandak, O’Neill, Light, and Fosco (2017) found that gaps exist between knowledge that focusing on the family is important for AAC intervention and action on the part of the speech-language pathologist in providing support to families. Iacono and Cameron (2009) found that many speech-language pathologists use more of a directive approach when assisting the families of students who use AAC. Often it is the intention of speech-language pathologists to provide

family centered AAC services but other factors, such as time and varying expectations, become barriers (Johnson, Inglebret, Jones, & Ray, 2006). In addition, the speech-language pathologist's lack of knowledge of AAC was noted to be an additional barrier (Mandak et al., 2017).

One concern about AAC that parents commonly reported was that it led to an increase in the parent's roles and responsibilities in the home environment (Angelo, 2000; Saito & Turnbull, 2007). These roles and responsibilities included maintenance of the device and implementation of the device (Angelo 2000; McNaughton et al., 2008). Additionally, it was noted that these parents desired more information and training as to how to better use the device in a variety of environments (Saito & Turnbull, 2007). The type of support or who should provide the support was not specified. Parette and Brotherson et al. (2000) and McNaughton et al. (2008) found that parents specifically sought information on maintenance of the device, sources of funding, and other services from which to receive support. However, Angelo (2000) found that almost half of the 114 parents who participated in the statewide Pennsylvania survey reported not having difficulty making the time to use a device at home. While this would suggest a change in the type of support parents are given, information is lacking in terms of how often the devices were actually used at home. To resolve these issues Angelo (2000) suggests that speech-language pathologists take time to monitor how the parents are integrating AAC in the home environment. This information would provide the speech-language pathologists with ways that the family might further need support in order for successful device use to occur in a wider variety of settings.

A study by Thunberg et al. (2011) used a family-centered model to evaluate the interaction pattern of a child with autism and learning disabilities, and how his interactions changed once an SGD was introduced. Thunberg et al. (2011) found that the child was more engaged during the morning circle time at school and communicated with his parents more

effectively at home after an SGD was introduced. This study supports the use of an SGD at both home and school to expand this child's communication in both settings. This study concluded with the realization that parents needed supports after an SGD was introduced, especially in terms of how to communicate with the child using the device.

Starble et al. (2005) sought to examine the positive effects of family-centered intervention and AAC use. The study focused on a four-year-old who used an AAC device at home and at school. The intervention consisted of three sessions with the parents at their home. The first session was spent gathering information about what the parents wanted their child to be able to communicate and the needs of the parents in terms of the AAC device. The second session focused on what the family had shared in terms of their needs, any difficulties with the device, and potential messages that they would like to have incorporated on the device. The last session focused on allowing the parents to practice using the device to gain skills related to becoming an effective communication partner. The goal of Starble et al. (2005) was to make sure that parents were active participants in supporting their child.

Parents have noted that speech-language pathologists need to be respectful, supportive, flexible, collaborative, and informative for the process of family intervention to be successful (Rini, 2002). Collaboration plays a large role in the overall satisfaction of families with the AAC device (Parette, Brotherson, et al., 2000). This collaboration is essential, however, because parental support is a main factor in contributing to a positive outcome for a child with an SGD (Lund & Light, 2006).

Without training and support for families of students with AAC needs, SGD abandonment is likely to occur (Parette, Brotherson, et al., 2000; Parette, VanBiervliet, & Hourcade, 2000). Parette, Brotherson, et al. (2000) conducted focus groups and interviews that were moderated by

speech-language pathologists. One group focused on families of children with AAC devices. Parents shared about training, education, and information in terms of AAC devices. It was noted that increased parent involvement was an important step in decreasing device abandonment. In addition, Parette, VanBiervliet, et al. (2000) sought to present an overview of family and cultural issues in the context of assistive technology, such as AAC. Parette, VanBiervliet, et al. (2000) found that, “Failure to consider family factors and to involve families in meaningful ways during AT [assistive technology] planning may result in abandonment of devices that are prescribed by teams” (p. 46). Involvement included voicing opinions about what parents viewed as being most beneficial for their child over time. Angelo (2000) found that AAC devices have been abandoned due to a lack of training, frustration with speech-language pathologists, and limited opportunities for the parent to have more involvement with the AAC process (Angelo, 2000). All of these unsupported demands and frustrations can put additional stress on the family, which may already be experiencing anxiety from the changes that occur from needing to support a child who is learning to communicate (Marshall & Goldbart, 2008) with a SGD.

SGD, School, and Families

Collaboration between a school speech-language pathologist and a family regarding the child’s SGD is an important aspect of a child being successful with a device. Two of the roles and responsibilities that ASHA lists for school-based speech language pathologists on their AAC Practice Portal are to “educate other professionals and caregivers on the needs of persons using AAC” and to “serve as an integral member of an interdisciplinary team working with individuals who use AAC and their families/caregivers” (ASHA, n.d.b). Collaboration between the school and families throughout the assessment and intervention is the responsibility of speech and language pathologists. Copley and Ziviani (2007) highlighted collaboration as being vital.

Collaboration helps to form achievable goals for the student, increase the overall competence of the team members, and better coordinate how the technology can transition between both environments which is essential for the success of the student using AAC (Copley & Ziviani, 2007).

DeFelice, H., Scheer-Cohen, A. R., and Hughes, D. M. (2014) provided a perspective on how speech-language pathologists and parents should collaborate so that AAC use is facilitated in both home and school. DeFelice et al. (2014) noted the importance of those supporting the student in various environments having the opportunity to practice using and navigating on the device. This type of support should come from the school, and parents should be trained even prior to the student if possible. When parents are fluent on a device, they can more easily support the child's use at home. The opportunity to use the device at school and at home will allow the child to generalize communication among a wide variety of settings. DeFelice et al. (2014) stress the importance of this collaboration being present throughout the assessment and intervention.

Rackensperger (2012) examined the role of families involved in supporting their children who use AAC in academic environments. Interviews through electronic mail were conducted over a span of ten months with eight young adults who used AAC. The questions were specifically guided towards gathering information about their experiences in secondary school, how they received any needed accommodations, and any dynamics in their family, which may have directly impacted their success academically. The researcher found that for these students, the parents used the AAC device as a form of support at home, which played a large role in each student's academic success. This was only possible for the parents who had received the necessary support and had a general understanding of the device (Rackensperger, 2012). These parents needed more than just AAC knowledge; however, they also had to stay current with any changes in school

dynamics and address school-based issues that impacted the education of their child (Houtenville & Conway, 2008). Students who have complex disabilities are most successful academically when parents remain involved and seek to use accommodations to support the learning at home (Rackensperger, 2012; Reed, Antia, & Kreimeyer, 2008; Rodgers, Weiner, Marton, & Tannock, 2009).

Kortz (1998) points to the importance of AAC transitioning from school to home in order for the device to become fully implemented. She suggested that the speech-language pathologist should set up various AAC activities in the home so that device use is occurring in a natural setting. Kortz (1998) noted, “Although clinicians historically have not delivered services in these kinds of locations, the impact of this type of service delivery can be greater because the AAC intervention will be more meaningful and motivating for the child and family” (p. 7). At the very least, Kortz (1998) stressed that the home to school connection is important and should be seen as a way to share information about home-based needs for the student that could be addressed at school.

Lund and Light (2007) analyzed various positive and negative factors that affected outcomes for individuals using AAC at home and at school. Negative attitudes were strongly identified as impacting an individual’s overall outcomes. Another barrier discussed was any breakdown or limitation in the AAC technology. This can then lead to overall dissatisfaction with the AAC device (Clark, McConachie, Price, & Wood, 2001). Parental support was a positive factor for many participants in the Lund and Light (2007) study. Service deliveries from speech-language pathologists were cited as being negative or positive depending on a multitude of factors. Lund and Light (2007) stated:

The aspects of service delivery cited as having an adverse effect were lack of availability of services, limited knowledge of professionals, lack of collaboration between professionals, and limited focus of goals. The aspects of service delivery that were cited as positively influencing outcomes were competent and knowledgeable professionals; training for families, facilitators, and teachers; and effective communication and collaboration between professionals, family, and school personnel (p. 331).

The collaboration of school personnel and family members has a definite impact on the overall outcome for a student.

Parents noted in McNaughton et al. (2008) that many of the professionals they interacted with displayed a lack of knowledge in the area of AAC, which resulted in others working with the student not understanding how to use the device. Sutherland, Gillon, and Yoder (2005) and McNaughton et al. (2008) noted a need for more training for speech-language pathologists in the area of AAC. It is important to acknowledge that the collaboration between family members and speech-language pathologists will require effort but the success of the student depends on this partnership (Lund & Light, 2007). It is important that speech-language pathologists do their best to remain sensitive to parents and their needs as they seek to support their child in learning an SGD (McNaughton et al., 2008).

When speech-language pathologists or educators are providing services to individuals who use AAC, they should consider both the consequences and outcomes that arise from using an AAC device (Angelo, 2000). This is important for speech-language pathologists to consider during both the assessment process and while providing intervention. Even amid consideration from speech-language pathologists, reports of frustration between family members and speech-language pathologists are found in the literature. A lack of family involvement in the assessment

process frustrated family members who reported having no choice in deciding on their child's SGD (Parette, Huer, & Botherson, 2001). Frustrations between speech-language pathologists and parents vary but frequently are due to lack of communication about the AAC device (Cress, 2004). Parents may see an AAC device as the one piece of technology that will span the communication gap for their child. The speech-language pathologist may see the device as a means to meeting educational objectives. Students benefit from combined perspectives.

Children with AAC needs requiring SGDs require specific support and assistance from speech-language pathologists. Speech-language pathologists complete assessments and provide the necessary intervention for children who need an SGD for both the school and home settings. Providing the appropriate support for and access to the device is imperative. When parents use devices with their children, the children have shown the ability to be successful in their communication efforts and their ability to perform well academically in school. If parents are an important part of children using SGDs, especially in terms of preventing device abandonment, there must be on-going open discussions and support between the speech-language pathologist and the child's parents regarding device usage. This will create an optimum scenario for success for the child's ability to communicate with an SGD device.

Purpose

The purpose of this research was to explore the support parents of students who use SGDs receive from school personnel. Specifically, the researcher inquired about what support the families were receiving, what support they would like to receive, and what support was beneficial.

Chapter 2

Method

This research sought to identify what SGD support is provided by speech-language pathologists to parents of children who use SGDs and what support these parents would like to receive in order to help their children use the devices at home.

Participants

The participants in this study included 19 parents who had a child from preschool age to grade twelve who used an SGD to communicate. While 37 parents selected that they wished to complete the survey, only 19 parents completed the entire survey. The demographic information obtained included: state of residence, gender of participant and child, age of participant, race of participant, grade of child when device was received, current grade of child, child's type of school, and child's diagnosis.

Survey

The researcher created the survey on the Qualtrics website (www.qualtrics.com). She requested feedback from a family with a child who has an SGD before finalizing the survey. After the feedback was gathered, some questions were rewritten and clarified.

The survey titled "Extension of School Augmentative and Alternative Communication Services to Home" was a 40-question survey including the demographic information. The survey included skip pattern logic so that depending on how the parent answered a question he/she was directed to a different set of questions. The survey sought information first about the assessment process for the child using the SGD. Then, information was gathered in terms of whether parents of students using SGDs were offered and/or provided with support on using the specific speech-generating device that their child was given. The questions then involved identifying what support

was provided, how much support was given, and who provided any supplemental support to these parents. This survey sought to identify the specific type of support parents wanted to receive regarding their child's SGD and how they wanted this support to be provided. Parents were asked how school SGD use compared to SGD use at home.

Procedure

The researcher used email and a social media site (i.e. Facebook) in order to distribute the survey to organizations to share with parents. In addition, an announcement about the survey was posted on the ASHA Special Interest Group (SIG) 12 community website for ASHA members to pass on to families. Organizations distributed the survey link and information about the survey in newsletters, websites, emails, and/or each organization's Facebook page. The organizations provided with information about the survey included: Prentke Romich Company (PRC), Tobii Dynavox, Autism Society of America, Organization for Autism Research, National Down Syndrome Society, United Cerebral Palsy, Neurofibromatosis Network, National Organization for Rare Disorders, Angelman Syndrome Foundation, United Mitochondrial Disease Foundation. In addition, a parent resource center in every state was contacted to distribute the survey. Not every organization was able to share the survey and many did not email back regarding the survey.

Chapter 3

Results

This study examined what supports were given to parents after their child received a speech-generating device and what supports the parents would have liked to receive about the speech-generating device. In order to participate in the study, the parents filled out an online survey. Of the 40 parents who responded to the survey, 37 parents started the survey and three parents selected that they did not wish to complete the survey. Of the 37 parents who chose to complete the survey, only 19 parents completed the entire survey. The other 18 parents abandoned the survey after the first or second question; therefore, limited to no information was gathered on those participants. The survey completion percentage for this survey was 51.4%.

Of those who did not complete the survey, 14 parents only completed the consent page and four parents were directed to the end of the survey since their child communicated in speech and/or limited manual language. With respect to the 40 questions in the survey, the number of parents who answered each question ranged from two to twenty-three parents. The percentages reported in this study represent the number of parents who answered that specific question rather than the number of parents who answered the survey in its entirety.

The survey gathered information on six topics. The survey collected information on demographics, assessment for speech-generating device, general information about SGD use, type and amount of support provided to the parents, type of support parents wanted to have been provided, and how the student's speech-generating device was used at school in comparison to home.

Demographic Information

In terms of whether the parent's child used an SGD or other modes of communication (i.e. gestures, vocalizations, speech, etc.), 23 parents responded. The parents then provided the type of communication device their child used by typing an answer. The results are shown in Table 1.

Table 1: *How the Child Communicates*

Response on whether the "child uses a speech- generating device to communicate"	Number of Participants	Mode of Communication (number of participants)
Yes	19	iPad (6) LAMP on iPad (2) TouchChat on iPad (2) PRC Accent & iPad (1) PRC Accent (3) NOVA Chat (1) Tobii-Dynavox (4) Wego (1)
No	4	Speech (1) Verbally & Few Signs (1) No response (2)

The parents provided information about how they learned about the survey. Out of the 19 parents, four found out through a social media site (i.e. Facebook), 12 from an organization's email, one from a newsletter, one from word of mouth, and one selected "other." The specific organizations were not reported.

All 19 parents provided information on their current state of residence. The results are shown in Table 2.

Table 2: *State of Residence*

State of Residency	Number of Participants
California	3
Colorado	4
Delaware	2
Florida	1
Illinois	1
Iowa	1
Maine	1
Missouri	2
Texas	1
Virginia	2
Wisconsin	1

The parents reported information on their own gender, gender of their child, own age, and own race. Out of the 19 parents, 17 were female, one was male, and one preferred not to answer. In terms of the child's gender, 15 parents reported that the child was male, three reported that the child was female, and one preferred not to answer. In addition, information on the parent's age was collected. The parents were provided with age ranges to choose from. Six parents were 30-39 years old, four were 40-49 years old, and nine were 50-59 years old. For race, the parents were able to choose all races that applied. Seventeen parents were white, one was African-American, and one was American Indian.

Parents provided information about the grade their child was in when he/she received the device and their child's current grade. Out of the participants, 16 parents noted that their child was in elementary school when the device was first received. This information is provided in Table 3.

Table 3: *Grade of Child Then and Now*

Grade of Child when the Speech-Generating Device was Received	Current Grade of Child
Pre-Kindergarten	Pre-Kindergarten
Pre-Kindergarten	Kindergarten
Pre-Kindergarten	1 st
Pre-Kindergarten	8 th
Kindergarten	3 rd
Kindergarten	8 th
Kindergarten	8 th
Kindergarten	12 th
1 st	2 nd
1 st	4 th
1 st	8 th
2 nd	2 nd
2 nd	4 th
2 nd	6 th
3 rd	11 th
4 th	5 th
6 th	8 th
8 th	10 th
11 th	12 th

The type of school that the child attended was gathered with 16 of the children attending public school, one attending private school, one attending public and private, and one being homeschooled. All 19 parents then selected an option for their child's diagnosis or wrote in the diagnosis if the diagnosis was not provided. This information is noted in Table 4.

Table 4: *Child's Diagnosis*

Diagnosis	Number of Children
Apraxia	1
Down syndrome	1
Autism spectrum disorder	5
Cerebral palsy	5
Autism spectrum and intellectual disability	1
Cerebral palsy and autism spectrum disorder	1
Autism spectrum disorder, epilepsy, and encephalopathic generalized epilepsy	1
Down syndrome, autism spectrum disorder, and attention-deficit/hyperactivity disorder	1
Down syndrome and autism spectrum disorder	1
Apraxia, epilepsy, and pervasive developmental disorder-not otherwise specified	1
Chronic, static encephalopathy	1

Assessment

The survey gathered information about the assessment that occurred in order for the child to receive the speech-generating device. The parents provided information about who completed the assessment. The parents who participated selected all individuals who were involved in the process. This information is provided in Table 5.

Table 5: *Who Completed the Assessment*

Role	Number of Participants
Speech Language Pathologist	16
Special Educator	2
School District	1
Personnel Working for Device Manufacturing Company	0
Physician	1
No Assessment	1
Other	4

The parents selected information about the location of the assessment and if multiple speech-generating devices were trialed. Once again, multiple answers were selected if applicable to the parent's situation. Four parents selected the child's school, 11 parents selected clinic, hospital outpatient, or private practice, and two parents selected both options. Two parents typed in the home as another location. In terms of speech-generating devices trialed, 11 parents said multiple devices were trialed; six parents said no other devices were trialed, and one parent said he/she did not know if multiple devices were trialed.

General Information about SGDs

The parents provided information as to the locations where the device is used more frequently. The 19 parents' responses are provided in Table 6.

Table 6: *Locations of High Use*

Location	Number of Participants
Home	11
School	15
Community Events Outside of School	6
Other	3

Of the 19 parents, 17 indicated that the SGD was brought home from school; while two of the parents said that the SGD remained at school. Both of those parents selected that the SGD was never brought home. In addition, information about how long ago the child received the SGD was gathered. The parents' responses are noted in table 7.

Table 7: *Time Frame of Receiving SGD*

Time	Number of Participants
Less than 6 months ago	2
6 months to 1 year ago	2
1 to 2 years ago	4
More than 2 years ago	11

The 19 parents provided information about whether their child's current SGD was his/her first SGD. Eight parents selected "yes" to the current SGD being their child's first SGD, while 11 parents selected "no" meaning that their child has had at least one previous SGD.

SGD Support

The parents selected whether they sought support in terms of how to use the SGD after their child received the device. In terms of whether support was sought, 17 parents sought support and two parents did not seek support. Of the 17 parents who sought support, the percentage of

parents who said support was then provided was 88.24%; however, 11.76% of parents stated that support was still not provided.

In regards to whether support was initially offered, without the parent asking, four parents responded. Half of those parents said support was offered and half selected that no support was offered. Information was then gathered in terms of how this support was provided from 17 parents. They selected all the ways that support was provided. This information is described in Table 8.

Table 8: *Ways Support was Provided*

Support Modes	Number of Participants	Percentage of participants
In-person Meeting	14	82.35%
Phone Conversation	3	17.65%
Online Video Conversation (i.e. Skype)	1	5.88%
Email	7	41.18%
Online Training Videos	4	23.53%
Other	4	23.53%

It is important to note that one of the parents who selected “other” stated that “the non-school based SLP who did the eval [evaluation] taught me how to program the app but my child’s school SLP and IEP team had no knowledge and needed training which continues to be an issue.” The parents then identified which personnel provided the supports. The parents selected all the members who they felt supported them in learning about the device. The responses of the 17 parents are shown in table 9.

Table 9: *Support Personnel*

Personnel	Number of Participants	Percentage of Participants
Speech Language Pathologist	11	64.71%
Special Educator	1	5.88%
General Education Teacher	1	5.88%
Device Manufacturer Online Representative	7	41.18%
Augmentative and Alternative Communication Representative	4	23.53%
Other	3	17.65%

The hours of support was solicited from the 17 parents. They chose from a variety of time intervals. Nine parents selected less than 3 hours of support; three parents selected 4 to 10 hours of support; two parents selected 11 to 20 hours of support; and three parents selected more than 20 hours of support. The parents then provided information on what form of support worked well and what support did not work. It is important to note that 17 parents responded to the question about what worked well and 11 parents responded to what did not work as well. This information is provided in Table 10 and Table 11 respectively.

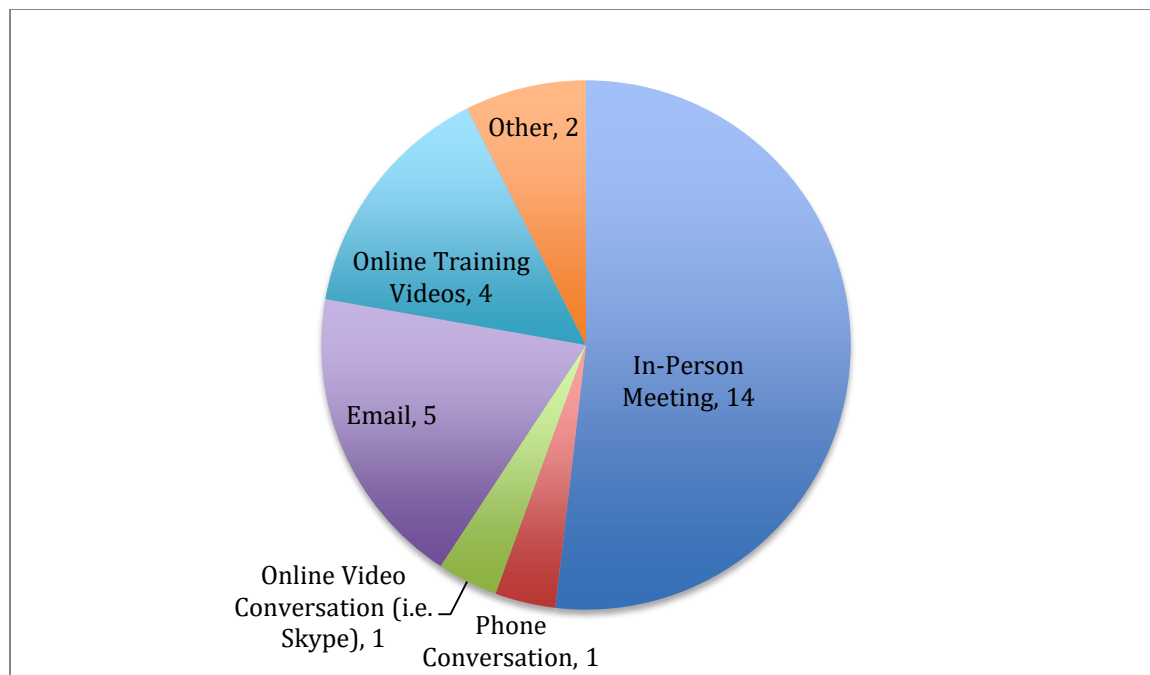
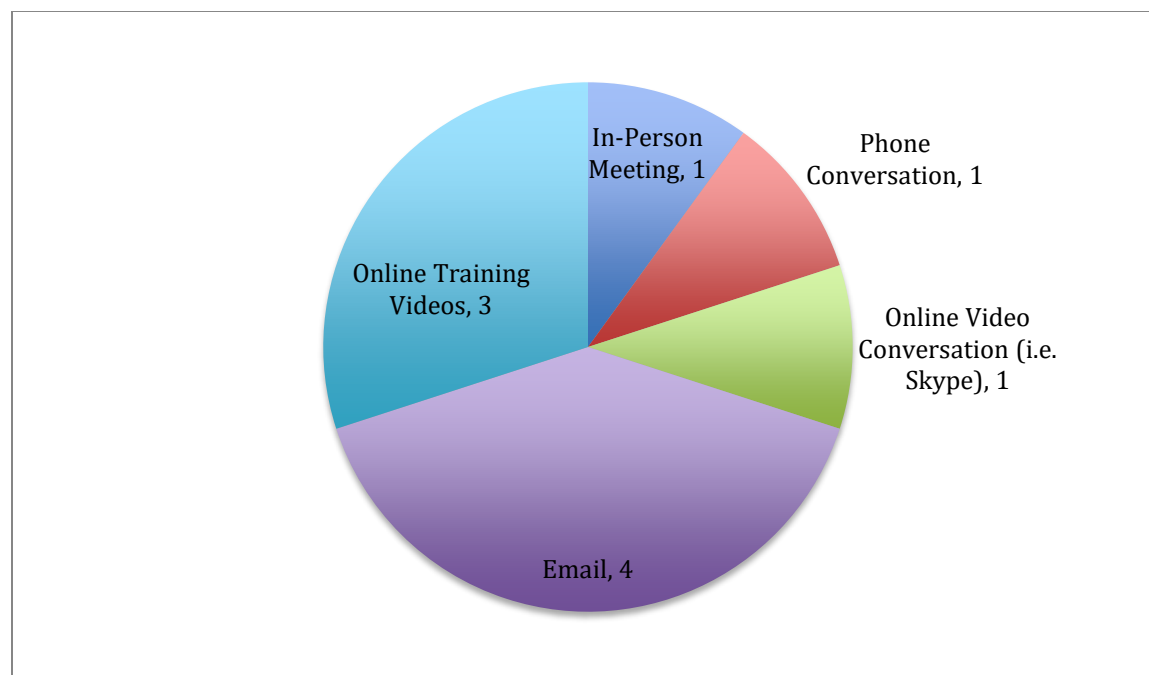
Table 10: *Mode of Supports that Worked Well*

Table 11: *Mode of Supports that Did NOT Work as Well*

The parents provided information about all the areas in which support was provided. The 17 parents chose all the areas that were applicable. The data is shown in Table 12.

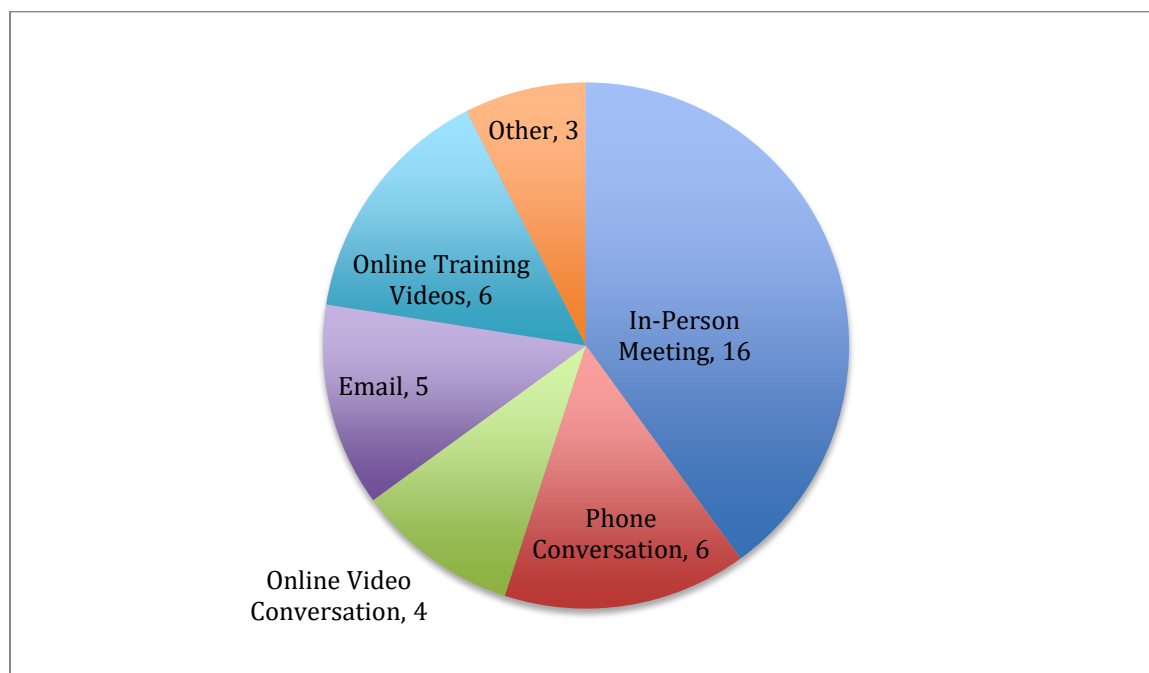
Table 12: *Areas of Support Provided*

Areas of Support	Number of Participants	Percentage of Participants
Help with Customizing the Language Software	13	76.47%
Help with Navigating the Speech-Generating Device	15	88.24%
Technical Support for the Speech-Generating Device	10	58.82%
Help with Supporting your Child's Use of the Speech-Generating Device	11	64.71%
Other	1	5.88%

The 17 parents then provided insight in terms of how they would have liked the support to be provided. One parent stated, “The SLP works very hard to support us but the company rep [representative] has dropped off and won’t return calls to either SLP or mom.”

This information is provided in Table 13.

Table 13: *Participants Desired Mode of Support*



The parents selected what they wished they knew more about in terms of the SGD device. 19 parents responded and their selections are displayed in Table 14.

Table 14: *Areas Participants Wish They Knew More About*

Areas	Number of Participants	Percentage of Participants
How to Customize the Language Software	9	47.37%
How to Navigate the Speech-Generating Device	4	21.05%
Technical Support for the Speech-Generating Device	9	47.37%
Help with Supporting your Child's Use of the Speech-Generating Device	9	47.37%
Other	1	5.26%

The parents then ranked those areas of support in terms of most critical (rank of 1) to least critical (rank of 5). This ranking system allowed for an “other” form of support to be listed if necessary. One parent said that the ranking system did not work for them. The information from 17 parents is provided in Table 15.

Table 15: *Ranking of Various Supports*

Areas	Percent of Participants Rank 1	Percent of Participants Rank 2	Percent of Participants Rank 3	Percent of Participants Rank 4	Percent of Participants Rank 5
Help with Customizing the Language Software	29.41%	11.76%	29.41%	29.41%	0%
Help with Navigating the Speech-Generating Device	17.65%	29.41%	29.41%	17.65%	5.88%
Technical Support for the Speech- Generating Device	17.65%	17.65%	29.41%	35.29%	0%
Help with Supporting your Child's Use of the Speech-Generating Device	29.41%	41.18%	11.76%	17.65%	0%
Other	5.88%	0%	0%	0%	94.12%

The parents then selected whom they wanted the support to come from. All 19 parents responded and the results showed that 73.68% chose a speech language pathologist, 15.79% chose a special educator, 5.26% chose a general education teacher, 31.58% chose a device manufacturing company representative, 68.42% chose an augmentative and alternative communication representative, and 10.53% chose other. For the category of “other,” one parent typed ABA therapist and the other parent shared about limited time being able to interact with the speech pathologist.

SGD Use Comparison of School to Home

Questions were focused on SGD use at home and at school, including information about the child and parent's use of the SGD. Information was collected in terms of how often the parent communicated using the SGD with their child and how often the child used the SGD to communicate. The responses of the 19 parents are shown in Table 16.

Table 16: *Parents Use/Child's Use of SGD Comparison*

Parent's Usage of SGD	Child's Usage of SGD	Number of Participants
Never	Never	1
Rarely	Rarely	2
Sometimes	Rarely	2
Sometimes	Sometimes	4
Often	Sometimes	5
Often	Often	5

Information was solicited about whether the SGD use is monitored when the student is at school. Of the 19 parents, 13 parents selected yes to the SGD use being monitored at school, two parents said that device use was not monitored, and four parents said that they were not aware if it was monitored or not. Out of the 13 parents who said that device use was monitored, five parents stated that it was recorded so change over time was monitored while eight parents stated that use was not recorded.

The parents identified the location where the child spent a majority of his/her school day. 18 parents answered and the information is provided in Table 17.

Table 17: *Child's Education Setting*

School Setting	Number of Participants
Full-Time General Education Room	1
General Education Room for More Than 50% of the Day	4
General Education Room for Less Than 50% of the Day	5
Full-Time Special Education (Resource Room)	8

Questions about speech-language service outside of the school were asked. Twelve parents stated that their child did receive language services outside of the school and seven parents stated that their child did not receive language services outside of the school. The setting for those parents who did receive language services outside of school was identified. Nine of the parents selected a clinic setting, one parents selected a hospital setting, and two parents selected “other.” Out of the two parents who selected “other,” one parent said private practice and the other parent said home. The final question asked on the survey was about whether the child still owned their device. Eighteen parents selected that their child did still own the device, and one parent selected that his/her child did not still own the device.

Chapter 4

Discussion

The purpose of this study was to examine the amount and type of support from schools that is given to parents of children who use SGDs to communicate. In addition, it sought to identify the type of support that parents would like to receive and how support could help with SGD use in the home environment. An online survey was used to collect data in hopes that the information gathered would be beneficial for speech-language pathologists as they seek to support the families of children who use an SGD.

Assessment of SGDs

Before supports can be considered, the assessment of the SGD must be considered. When looking at SGD assessments it is vital to look at who completed the assessment, where the assessment was completed, and parent's insights on the assessment process. An assessment was completed for all but one child. It is notable that 13 of the parents said that the assessment for their child was completed at a clinic, hospital (outpatient), or private practice, while only five parents' children had an assessment at school. It is important to note, however, that an assessment outside the school was at times completed due to the school not wanting to do the assessment. One parent stated, "Our family has had sole responsibility for acquiring the device, training school staff to use it, and convincing school staff to use it." This was supported by another parent who stated, "I had to push my son's school into getting the device by doing a private eval [evaluation] out of frustration with school's continued use of low-tech (pictures) supports...The difficulty now is getting the school staff trained on the device and to actively use the device." A speech-language pathologist was involved in the assessment for 17 of the students. One parent did report that the assessment was done by himself/herself. This parent later added an additional

comment that he/she completed the assessment because the school was not willing to provide those services. This matches McNaughton et al. (2008) who found that parents reported that it was sometimes put on them to try to obtain services for their child and that they needed to become the AAC expert. This lack of support from speech-language pathologists in the schools may be due to speech-language pathologist's lack of knowledge in this area. This finding is in agreement with the results of a survey that Stark, Kent-Walsh, and Binger (2007) completed. In that study, school-based speech-language pathologists ranked themselves as low in the area of AAC expertise.

A majority of parents reported frustration with schools in this study in terms of either assessment or intervention involving the SGD. One parent stated that, "The SLP in my son's school does not have a lot of knowledge about his device. I receive very limited support from our SWAAC team at school. The majority of the support I received for the device was provided by my son's private SLP outside of the school." Even when assessments were not completed in the child's school, the school speech-language pathologist is still expected to have SGD knowledge to provide intervention and supports in the school setting as needed. Parents were frustrated with the speech-language pathologist's lack of knowledge in SGDs. Lack of knowledge may not be the only reason why speech-language pathologists do not recommend SGDs. Some schools have policies and/or practices in place where the district suggests other forms of AAC due to cost of SGDs. Schools want to try to save money and unfortunately, this can lead to decisions regarding what device to recommend for a student to be based cost more than the needs of the student.

It is best practice in assessment to provide opportunities for potential users of AAC to try a variety of devices. In this survey it was reported that not all children had the opportunity to try multiple devices. It is possible to borrow trial devices from device manufacturing companies;

however, this may not be well known. This could indicate the need for device manufacturing companies to make trial devices more available or this could have arisen from a lack of knowledge by speech-language pathologists about the various SGD options and how to get them for trials. While speech-language pathologists may participate in a class about AAC, this does not necessarily include opportunities to explore various SGD options. To best match a student with a SGD, knowledge of the existing SGDs must be present. Speech-language pathologists should do their best to explore the existing resources online or in their districts about SGDs. Sutherland et al. (2005) and McNaughton et al. (2008) both emphasized the fact that speech-language pathologists should receive training in order to increase their knowledge. This is important so that students who need an SGD are being advocated for. Multiple devices should be trialed so that the student can find his/her most effective form of communication.

A lack of multiple devices being trialed could be due to a decreased knowledge of various SGDs. This information has begun to be shared at conventions, such as the American Speech-Language- Hearing Association Convention, where SGD companies share their products. However, this reaches only the speech-language pathologists who are able to make it to the conferences. More support could be given by device manufacturing companies either through attending speech-language pathology graduate programs or by holding in-services in school districts for speech-language pathologists to attend and expand their knowledge.

Speech-language pathologists in the schools can find information regarding SGDs online so that they are able to best serve those students who use or need SGDs to communicate. The websites for the Prentke Romich Company (<https://www.prentrom.com/>) and Tobii Dynavox (<https://www.tobiidynavox.com/en-us/>) both provide valuable information for speech-language pathologists regarding device options. Through the websites, it is impossible to get in touch with

consultants and find out about trainings. These websites may also provide the speech pathologists with resources and supports that can be passed on to the parents of the child. The ASHA Practice Portal is also an excellent resource for speech-language pathologists relative to AAC. These websites online may be an important first step for speech-language pathologists in order to increase their knowledge and comfort in supporting students with SGDs.

Supports Given to Parents

Information about the supports given to the parents varied, however, some trends were noted. A majority of parents, 17 out of 19, stated that they sought out support, which may have affected the amount and type of support provided. The results suggest that seeking support is a beneficial first step for parents, since it led to 88.24% of the parents receiving support. This finding supports the findings of Lund and Light (2007) who reported that parents needed to be vigilant advocates ensuring that their child received the necessary support. Seeking support could lead to collaboration, which can lead to a more positive outcome. Parents may have asked for this support because they did not receive adequate support initially. These parents may have already had experiences that showed them that they needed to be advocates for their children and for themselves in order to receive the necessary support. Since a majority of parents stated that the SGD did go home with the child, then basic training on the device should be provided.

For those parents who did not seek support, support was only offered half of the time. This is concerning since the expectation would be that support is always provided. A possible reason for support not being offered when it was not sought out may be due to the speech-language pathologist's lack of knowledge in the area of SGD and intervention for an individual who uses an SGD. One parent wrote, "School personnel need training. Device goes to school but if staff don't know how it works it's not helpful." For some parents, the lack of support from personnel

led them to decide to remove their child from the school system. One parent who decided to home school his/her child shared, “I found that she is doing much better here at home learning her device than she ever did in her four years in public school. Her speech therapist in school was hesitant to use her device & often did not.” It is plausible to suggest that support is at times not provided due to the speech-language pathologist not knowing how to operate the device. It may be that parents who continuously advocate and request support are the ones who receive the support. However, support in the area of SGD should be provided regardless of a parent’s advocacy.

The modes and personnel involved with support were explored in the study. The kind of support that 14 of the parents received was in-person meetings with email being second at five parents. It is positive to note that such a high number of parents received in-person support, since that option may be seen as the most time consuming for speech-language pathologists. Email may be the second most frequent mode due to the ease of email as a form of communication. Since speech-language pathologists often feel like they are busy, email may become the way of communicating with parents. Support usually came from the speech-language pathologist, a device manufacturer online representative, or an augmentative and alternative communication representative. An augmentative and alternative communication representative refers to a specialist in the area of AAC. Some school districts had an individual or team come in who was more specialized in the area of SGDs. One parent reported a positive experience and shared, “Without my SLP who is extremely motivated I would be completely lost! And she is self-taught—rep [representative] to help her would be great. Tech support is very good however.” This stresses the importance of these different support personnel communicating to ensure that the best support can be provided to the family. Communication between the device company

representatives and the speech-language pathologist may help to increase the speech-language pathologist's knowledge in the areas of SGDs since the representatives of device companies are experts in the various devices that their company sells.

While the support personnel and mode of support varied, the amount of support given was often three hours or less of support. Given the complexity of many SGDs, three or fewer hours do not seem adequate. A majority of the parents felt that the in-person meetings worked well as the mode of support. This supports what Starble, et al. (2005) found. In that study, in-person support was provided to the parents and was shown to be beneficial. This form of support may be beneficial because the SGD is also present so that more modeling and hands-on practice can occur. This result in the study should be seen positively, since that is how a majority of parents received support. However, email was ranked the highest with four parents selecting that email as the mode of communication that did not work well. Email may not have worked as well because it is difficult to provide support about a device without being present with the device so that different aspects of the device can be modeled for the parent. Speech-language pathologists may have decided to use email due to their own lack of knowledge or it could have been because of not feeling like they had the time to do in-person meetings. This is a reminder that every parent's learning style is different and the mode of support that they desire should be taken into account. For example, five parents noted that email worked well as a mode of support, while four other parents stated that it did not work as well. This could be due to limited access to Internet or decrease comfort in technology. Allowing parents to communicate their preferred mode of communication is vital. Parents who talked about what supports worked well did not always answer the question about the supports that did not work well. This is most likely due to them liking the mode of communication that was used.

In terms of the areas of support, the area that was most frequently addressed was help with navigating the SGD. This is a crucial skill in understanding the device. Parents should be supported in their efforts to have an understanding of how to use the device that even goes beyond their child's knowledge so that they are able to model the correct use. DeFelice (2014) noted this as an important factor for successful implementation of the device to occur in both the home and school environment. The least frequently addressed area of support was the technical support for the SGD. Technical support could refer to the parents wanting support about how to find information that has been erased. Support can be provided to parents in multiple ways due to current technology. Speech-generating device companies (i.e. Prentke Romich and Tobii Dynavox) offer online support, which could be beneficial for both families and speech-language pathologists in order to help better understand devices. Technical support information most often comes from device company representatives, which only provided support for seven of the parents. Most likely, if device company representatives are more involved in providing support, then concerns regarding technical support can be addressed more frequently.

Supports Requested by Parents

The areas in which the parents said that they received less support were the areas where they wanted more support. These included the following: customization of the language software, technical support for the SGD, and support of child's use of the SGD.

The importance of different kinds of supports requested varied from parent to parent, which once again denotes the importance of understanding the family and seeking to find out what supports the parents would like to receive and in what mode they would like the support. This also points to the individual needs of students and families. This need to focus on the family was also noted by Marshall and Goldbart (2008) and Cress (2004). By taking the time to see the

SGD from the parent's point of view, the speech-language pathologist may be able to make a large impact in terms of decreasing the number of device abandonments and increasing a parent's overall positive perceptions of AAC. School speech-language pathologists can still provide individualized support even with their time constraints, such as with AAC parent groups and/or AAC newsletters. The AAC parent groups could allow parents to come and receive demonstrations of various SGDs and receive some one-on-one support as needed. This could be completed with just one school or a school district. Another way that support could be provided is through an AAC newsletter, where the speech-language pathologist can answer frequently asked questions and provide some tips for communication at home. These steps could go a long way in providing support for families who may feel lost in terms of knowing what to do with the SGD. In addition, this would help the speech-language pathologists to increase their overall knowledge in terms of SGDs and grow in their expertise.

The parents provided information about the personnel they would like to provide their support. A speech-language pathologist was first choice at 73.68% of parents. Parents want to be able to communicate about the SGD with the speech-language pathologist. The speech-language pathologist is already working with their child and parents desire that collaboration to occur with them. Since speech-language pathologists completed most assessments, it makes sense that parents would then desire to receive support from them. Speech-language pathologists need to be knowledgeable about SGDs to be able to provide this support. Unfortunately, many parents reported that speech-language pathologists were not well informed about the SGD. One parent stated concerns about the education of speech-language pathologists. The parent wrote:

Most have absolutely no training, or experience and have little or no knowledge how to communicate with an augmentative device user. In my opinion, this should be

MANDATORY training in college to get a degree in speech pathology. This should be fixed, it is a huge problem. We have only had one speech therapist in 13 years of public school who had a good understanding of how to communicate with a child who uses a device for his/her voice. Shame on the colleges and universities for not including this training in their required curriculum.

This parent felt that the lack of knowledge about SGD begins at the university level. It is within the scope of practice and an obligation of the speech-language pathologist to be knowledgeable about AAC, which includes SGDs. This area may not be taught in enough depth in programs for speech-language pathologists to feel comfortable providing intervention for students using SGDs.

A connection could be made between the parent's use of the SGD and the child's use of the SGD. In every case, the child was reported using the SGD to communicate as much as or as little as the parents. This shows the power that parents hold in terms of device usage in the home environment. Without the proper training and support, parents may be unaware of how to use the SGD at home and what role they should have in using the SGD. In terms of the supports provided, 11 parents out of 17 selected the option about supporting the child's use of the SGD. This shows that parents are not consistently provided with information; however, it was ranked frequently as the first or second most critical area in which receive support. This is most likely due to the parent's desire to understand how to use the device, so he/she can then encourage his/her student to use the device. As parents gain knowledge in this area, higher levels of device use at home could occur. It should not be the case that the device is never used at home when the supports are provided; however, it cannot be ruled out that the needs of caring for a child with complex communication can make use of an SGD at home more difficult and potentially inconsistent. This study helps to validate that parents do play a role in their child's use of the

SGD. Parents should be trained to use instructional strategies and aided input and modeling, which were described as beneficial strategies by Sennot et al. (2016) and Binger and Light (2007).

Clinical Implications

This study was created in order to help speech-language pathologists identify the types of supports that parents are hoping to receive after their child receives an SGD. Speech-language pathologists working in a variety of settings can use this information to improve the way they serve families where a child has an SGD because the data comes from parents of children who use SGDs.

Speech-language pathologists in the school should have knowledge regarding SGDs in order to provide assessments and interventions for those students who have complex communication needs. Speech-language pathologists should keep parents involved throughout the entire process and provide support in-person, since a majority of parents appreciated that time with the speech-language pathologist. It is not so much that speech-language pathologists need to spend a specific number of hours to support the family but rather provide consistent support and support that meets a family's needs. If speech-language pathologists do not feel knowledgeable about SGDs, it may be beneficial to collaborate with others in the area or contact device manufacturing companies to learn about the various types of SGDs. A lack of knowledge is apparent to parents and results in frustration from the parents. Parents wanted the support in regard to customizing the language software and supporting the child's use of the SGD to come from the speech-language pathologist. Those two areas were emphasized as being most critical.

Different families will need different modes of support in order to best understand the SGD, and it is important to provide what is needed. The speech-language pathologist can be prepared to provide the support needed by understanding the SGD and collecting information

sheets on the SGD. Speech-language pathologists and the parents should come together and create a plan in which both members decide on consistent meetings so that what is being taught at school can also be highlighted in the home environment by the parent. These meetings can also be times to check in with the parents and see how they are adapting to the SGD and what other supports they would like to receive. Communication is an ongoing process. Modes of communication should be expanded though to include more than in-person collaboration. It can include email and training videos as modes of communication and training.

It is important that speech-language pathologists consistently take the needs of the family into consideration and seek to find out what support the parents would like to receive. They need to find the time to meet with these parents as they are also trying to adjust to this new change. Speech-language pathologists should recognize their role as the AAC provider and collaborator in the schools and provide the supports in order to help the student succeed both at school and at home. Their role includes having a knowledge base of SGDs so that they are able to provide the appropriate supports. Speech-language pathologists need enhanced knowledge about the various device options and how to implement device use across settings.

Limitations

One limitation of the study is the number of participants and only using one mode of communication to reach participants, which limits generalization of the results. Parents who have children who use SGDs to communicate can be a difficult group to gather information from due to other time commitments. The survey was only available online. However, paper copies may have increased the participation. For some parents this may have been an easier way to complete the survey and would have expanded the type of parents who would have been able to take the

survey. In addition, more participants may have been gathered if additional incentives were offered. This may have helped them to understand an additional benefit of taking the survey.

Other limitations include the lack of variance, which also limits generalization of the results. In addition, gender should be considered since the data came from at least 17 females (mothers) and focused on the experiences of at least 15 male children (sons), which may have skewed the data. Also, race should be taken into account. Seventeen participants were white, which limits the possibility of analyzing cultural diversity. Information was not gathered about the specific organization that the participants heard about the survey from, so it is not possible to identify each organization that released the survey to its members. Another limitation is that only parents who were connected to these different organizations received information about my survey, unless it was shared by word of mouth. Most likely this sample represents those parents who are proactive and well informed in this area due to their connections with support groups.

The survey flow and lack of additional information to create a comprehensive picture of each family were noted as limitations. The flow of the survey could have confused some participants. Participants would at times select “other” in a question and type an answer that would not correlate with that question. The participants may have been confused about the wording of questions, which could have impacted the results. In addition, some additional information could have been gathered about how long support was provided after the child received the device, how often the parents and speech-language pathologist communicate about progress, why the first SGD was abandoned if the child has had multiple devices, and if activities are ever sent home from the speech-language pathologist for the child and parents to do together. These questions would help to gather a more complete picture of SGD support from these families.

Future Research

This research should be extended to include more participants and additional information. For example, more information about the assessment process such as who requested the assessment, how involved the family was, and who funded the device would be useful. It would be beneficial for a survey to be conducted where both the families and the speech-language pathologists serving them completed the survey so that different perspectives could be gathered. This could provide an even better picture as to how the school to home partnership should work. This would include focusing on areas, such as school barriers, family variables, knowledge of SGDs, and connection between preferred mode of training and type of support needed. By providing the different views between the families and speech-language pathologists, it would show what partnerships in the school currently look like.

Future research could trial a variety of ways in which to provide parent's with SGD support when time constraints due to jobs or other commitments make communication and training difficult. That study could analyze whether added incentives could be beneficial with training, such as making an SGD training a school-wide event for all parents where food is offered and the training is held on a weekend.

In addition, future research could include analyzing how different family variables (number of siblings, jobs, other time constraints, perception on AAC knowledge, etc.) may impact the type, level, and amount of support needed for these families. This may provide information, which would be important for speech-language pathologists to gather when providing an assessment for a family in order to better understand how support should be provided given that additional information.

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Appendix A

Extension of School Augmentative and Alternative Communication Services to Home

(Exported from Qualtrics)

Q1 Information Statement:

The Department of Speech-Language-Hearing: Sciences and Disorders at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that even if you agree to participate, you are free to withdraw at any time without penalty.

We are conducting this study to better understand the supports that parents of children who use speech generating devices receive after the child obtains the device. This will entail your completion of a survey. Your participation is expected to take approximately 15-20 minutes to complete. The content of the survey should cause no more discomfort than you would experience in your everyday life.

Although participation may not benefit you directly, we believe that the information obtained from this study will help us gain a better understanding of how speech pathologists, specifically in the school system, can best serve and support parents of children who use speech generating devices. Your participation is solicited, although strictly voluntary. Your name will not be associated in any way with the research findings. No identifiable information will be collected.

It is possible, however, with Internet communications, that through intent or accident someone other than the intended recipient may see your response. If you would like additional information concerning this study before or after it is completed, please feel free to contact us by phone or mail.

Completion of the survey indicates your willingness to take part in this study and that you are at least 18 years old. If you have any additional questions about your rights as a research participant, you may call (785) 864-7429 or write the Human Research Protection Program (HRPP), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email irb@ku.edu.

Sincerely,

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- ☐ I wish to complete the survey.
- ☐ I do not wish to complete this survey.

Q2 Are you the parent to a child (Preschool to grade 12) who uses a speech-generating device to communicate?(Note: For the remainder of this survey, speech-generating device refers to a communication application on a tablet/iPad, or an augmentative alternative communication device, which produces an audible voice that the child uses in order to communicate to others.)

- ☐ Yes. What kind of device? (Please specify) _____
- ☐ No. How does your child communicate? (Ex: picture book, PODD book, etc.)

Q3 How did you learn about this survey?

- ☐ Online through a social media site (i.e. facebook)
- ☐ Email from a device company (i.e. Prentke Romich, Tobii-Dynavox)
- ☐ Email from an organization
- ☐ Newsletter
- ☐ Word of mouth
- ☐ Other _____

Q4 What State do you live in?

Q5 What is your gender?

- ☐ Male
- ☐ Female
- ☐ Prefer not to answer

Q6 What is your child's gender?

- ☐ Male
- ☐ Female
- ☐ Prefer not to answer

Q7 What is your age?

- ☐ 18-29
- ☐ 30-39
- ☐ 40-49
- ☐ 50-59
- ☐ 60 or older

Q8 What is your race?

- ☐ White
- ☐ African-American
- ☐ American Indian
- ☐ Asian
- ☐ Alaskan Native
- ☐ Native Hawaiian or Pacific Islander
- ☐ Other: _____

Q9 In what grade did your child receive his or her speech-generating device?

- ☐ Preschool
- ☐ Kindergarten
- ☐ 1st Grade
- ☐ 2nd Grade
- ☐ 3rd Grade
- ☐ 4th Grade
- ☐ 5th Grade
- ☐ 6th Grade
- ☐ 7th Grade
- ☐ 8th Grade
- ☐ 9th Grade
- ☐ 10th Grade
- ☐ 11th Grade
- ☐ 12th Grade

Q10 What Grade is your child in now?

- ☐ Preschool
- ☐ Kindergarten
- ☐ 1st Grade
- ☐ 2nd Grade
- ☐ 3rd Grade
- ☐ 4th Grade
- ☐ 5th Grade
- ☐ 6th Grade
- ☐ 7th Grade
- ☐ 8th Grade
- ☐ 9th Grade
- ☐ 10th Grade
- ☐ 11th Grade
- ☐ 12th Grade

Q11 What type of school does your child attend?

- ☐ Public
- ☐ Private
- ☐ Charter
- ☐ Homeschool
- ☐ Other: _____

Q12 What is your child's diagnosis?

- ☐ Down syndrome
- ☐ Cerebral Palsy
- ☐ Autism Spectrum Disorder
- ☐ Mowat-Wilson Syndrome
- ☐ Neurofibromatosis
- ☐ Angelman Syndrome
- ☐ Mitochondrial Disease
- ☐ Other: _____

Q13 NOTE: Unless otherwise noted, you may select more than one answer for the rest of the entire survey.

Who completed the assessment for the speech-generating device?

- ☐ Speech Language Pathologist
- ☐ Special Educator
- ☐ School District
- ☐ Personnel working for device manufacturing company
- ☐ Physician
- ☐ No assessment
- ☐ Other: _____

Q14 Where was the assessment done?

- ☐ Child's school
- ☐ Clinic, hospital outpatient, or private practice
- ☐ Other: _____

Q15 Were multiple speech-generating devices trialed during the assessment process?

- ☐ Yes
- ☐ No
- ☐ Unknown

Q16 Where does your child use his or her speech-generating device the most?

- ☐ Home
- ☐ School
- ☐ Community events outside of school
- ☐ Other: _____

Q17 Is the speech-generating device brought home each day?

- ☐ Yes
- ☐ No

Q18 If no, (select one)

- ☐ The device is never brought home
- ☐ The device is brought home at least once a week
- ☐ The device is brought home about 1 to 2 times a month
- ☐ The device is brought home about every other month

Q19 How long ago did your child receive the speech-generating device? (select one)

- ☐ Less than 6 months ago
- ☐ 6 months to 1 year ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago

Q20 Is this your child's first speech-generating device?

- ☐ Yes
- ☐ No

Q21 After your child received the speech-generating device, did you seek support as to how to use the speech-generating device?

- ☐ Yes
- ☐ No

Q22 Was support provided?

- ☐ Yes
- ☐ No

Q23 After your child received the speech-generating device was support offered to you?

- ☐ Yes
- ☐ No

Q24 How was the support provided?

- ☐ In-person meeting
- ☐ Phone conversation
- ☐ Online video conversation (i.e. Skype)
- ☐ Email
- ☐ Online training videos
- ☐ Other: _____

Q25 Which personnel provided the supports?

- ☐ Speech pathologist
- ☐ Special educator
- ☐ General education teacher
- ☐ Device manufacturer online representative
- ☐ Augmentative and alternative communication representative
- ☐ Other: _____

Q26 About how many hours of support did you receive? (select one)

- ☐ Less than 3 hours
- ☐ 4-10 hours
- ☐ 11-20 hours
- ☐ More than 20 hours

Q27 In terms of how support was provided, what worked well?

- ☐ In-person meeting
- ☐ Phone conversation
- ☐ Online video conversation (i.e. Skype)
- ☐ Email
- ☐ Online training videos
- ☐ Other: _____

Q28 What did not work as well?

- ☐ In-person meeting
- ☐ Phone conversation
- ☐ Online video conversation (i.e. Skype)
- ☐ Email
- ☐ Online training videos
- ☐ Other: _____

Q29 In what areas was support provided?

- ☐ Help with customizing the language software
- ☐ Help with navigating the speech-generating device
- ☐ Technical support for the speech-generating device
- ☐ Help with supporting your child's use of the speech-generating device
- ☐ Other: _____

Q30 How would you have liked support to be provided?

- ☐ In-person meeting
- ☐ Phone conversation
- ☐ Online video conversation (i.e. Skype)
- ☐ Email
- ☐ Online training videos
- ☐ Other: _____

Q31 What do you wish you knew more about in terms of the speech-generating device?

- ☐ How to customize the language software
- ☐ How to navigate the speech-generating device
- ☐ technical support for the speech-generating device
- ☐ Help with supporting your child's use of the speech-generating device
- ☐ Other: _____

Q32 Please rank the following areas of support in terms of what you see as most critical to receive support in? (1=most critical, 4=least critical)

- _____ Help with customizing the language software
- _____ Help with navigating the speech-generating device
- _____ Technical support for the speech-generating device
- _____ Help with supporting your child's use of the speech-generating device
- _____ Other: _____

Q33 Who would you want to receive support from?

- ☐ Speech pathologist
- ☐ Special educator
- ☐ General education teacher
- ☐ Device manufacturing company representative
- ☐ Augmentative and alternative communication representative
- ☐ Other: _____

Q34 How often do you use the speech-generating device to communicate to your child? (select one)

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often

Q35 When your child is home, does he or she use her speech-generating device to communicate with you? (select one)

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often

Q36 Is the use of the speech-generating device monitored at school?

- ☐ Yes
- ☐ No
- ☐ Unknown

Q37 Is this recorded so that you can see change over time?

- ☐ Yes
- ☐ No

Q38 Where does your child spend his or her day in the education program? (select one)

- ☐ Full-time general education room
- ☐ General education room for more than 50% of the day
- ☐ General education room for less than 50% of the day
- ☐ Full-time special education (resource room)

Q39 Does your child receive language services outside of the school?

- ☐ Yes
- ☐ No

Q40 What is the setting?

- ☐ Clinic
- ☐ Hospital
- ☐ Other: _____

Q41 Does your child still have the device?

- ☐ Yes
- ☐ No

Q42 Please list any additional information you would like to add here. Also, if you wish to remove your responses please state that below.
